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EMPOWERS PEOPLE WITH DISABILITIES



EMPOWERED!

A report on disability, inclusion
and human rights

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MyRight is the Swedish disability movement's umbrella organisation for international development work, working to ensure that people with disabilities around the world are able to access their rights.

MyRight's vision is a world where all persons with disabilities enjoy equal opportunities to dignified lives within inclusive societies.

Read more about MyRight's work at www.myright.se

This report has been designed with the aim of being accessible to everyone. If you have any thoughts or comments on the accessibility of this report, contact MyRight at info@myright.se

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Cover photo: Yamuragiye Victoire is carrying a load of grass on her head. There are two other people carrying grass walking behind her. All of them have white canes. The photo was taken in Rwanda by Mia Munkhammar.

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Impairment and disability are not the same thing

An impairment means that a person has a lasting impairment of a physical, mental, intellectual or sensory function. The impairment may arise as a result of malnutrition, vitamin deficiency, illness or injury, be congenital or have occurred after birth. A person's impairment may be visible or it may not.

Disabilities are the limitations and obstacles that a person encounters in relation to their surroundings and that prevent their full participation in society on equal terms with others. A disability is something that arises in the interaction between a person with an impairment and surrounding society.

The term **accessibility** is used to describe how well things function for persons with disabilities. This includes the physical design of premises and access to and the design of information.

Rights holders and **duty bearers** are key concepts in work on human rights. The individual entitled to the right is called the rights holder. The person/people with a duty to ensure that the rights holder has their rights met is called a duty bearer. In this report, duty bearers are government agencies and states.



A group of people demonstrating on a street in Kathmandu, Nepal. Several of them are carrying a banner with writing in Nepali. There is also text saying "Nepal Disabled Human Rights Center". Photo: Lina Lystad

Summary

Human rights apply to all, but persons with disabilities often do not have full access to their rights. Discrimination, inaccessibility, prejudice, ignorance and a lack of resources mean that many persons with disabilities live in poverty with little opportunity to participate in society or to influence the situation in which they live.

Many persons with disabilities have no opportunity to support themselves through work or through a functioning welfare system. This leads to greater poverty, discrimination and vulnerability.

Women and girls living with disabilities are at risk of double discrimination and run a particularly high risk of suffering poverty. They face a number of obstacles that make it more difficult for them to participate in decision-making processes. This is the case not only in politics but also in many organisations working with rights issues.

Accessibility is essential for persons with disabilities to be able to exercise their human rights. Accessibility is also essential to being able to live independently and participate fully and equitably in society.

The obstacles faced by persons with disabilities in engaging with surrounding society make it difficult for people to exercise their rights. This may involve the ability to participate in elections, the right to inherit or to speak for oneself.

Sometimes there is good legislation in place but it fails to be implemented properly. This may be due to unwillingness, a lack of resources or a lack of knowledge. There are often practical obstacles and a lack of accessibility in the way. An election campaign, a polling station or a ballot paper can all be inaccessible and people may thus be unable to exercise their right to vote in an informed manner. Even where the right to vote is universal, some people may be legally incapacitated due to their impairment and thus lose the right to vote. Disability organisations take on many different

roles. Sometimes they are geared towards providing services not offered by the public sector, such as support in schools, interpreting services or assistance. They often act as schools for democracy and provide practical experience of leadership. Disability organisations also often play a crucial role in breaking the isolation in which many persons with disabilities live.

Organising themselves enables persons with disabilities to join forces, boost their autonomy, gain awareness of their rights and engage in advocacy towards decision-makers and those in power. Umbrella organisations that gather different disability organisations together play an important role in identifying common objectives for advocacy and using shared resources – economic and human. When attempting to change minds, it is often easier for people to take on board one shared message. Organising enables people to play a part in changing the society in which they live and improve the conditions in which they, and others, live.

Supporting and cooperating with disability organisations around the world means we can help to improve the lives of more people. Together, we strengthen the global disability movement and help to reduce poverty and exclusion across the globe.

Applying a disability perspective or involving persons with disabilities in an organisation's operations is not difficult. There are many organisations with a great deal of expertise and experience and there are good tools available to use.

The 2030 Agenda with its Sustainable Development Goals (SDGs) clearly states global development should leave no one behind. Taking a rights-based approach and working with the support of the Convention on the Rights of Persons with Disabilities will bring us closer to achieving the SDGs.

Foreword

"In strong organisations, informed and strong individuals can stand up for and assert their rights."

MyRight's vision is a world in which everyone with an impairment enjoys equal rights and opportunities to lead a life of dignity, free from poverty in an inclusive society.

We know how important it is to have strong organisations to strengthen individuals' rights and give them the opportunity to escape poverty. In strong organisations, informed and strong individuals can stand up for and assert their rights before decision-makers. The organisations often act as platforms where persons with disabilities can make their voices heard and influence their own lives and those of others, and ultimately escape poverty.

My way into development cooperation was via the Swedish National Association of the Deaf's (SDR) MyRight project in Sri Lanka. SDR collaborated with a Sri Lankan sister organisation with support from MyRight. I saw how important this partnership was, how our shared experiences of disability and discrimination meant we could understand each other, even though we came from different countries and our lives were different. It was clear that the partnership between the Swedish and the Sri Lankan organisation was a major contributing factor behind several of the successes of the disability movement in Sri Lanka.

People with disabilities have been excluded from international efforts and have not been able to share in the reduction in poverty and the socio-economic progress made in the world. MyRight works to ensure that questions that concern people with disabilities are included in international development cooperation to a greater extent.

There are a number of important and excellent tools to achieve change. The Convention on the Rights of Persons with Disabilities and the Agenda 2030 with its Sustainable Development Goals are good tools for eliminating disabilities and facilitating inclusion across the globe.

In this report, we aim to demonstrate that if we are given the right conditions, we can achieve greater empowerment, independence and freedom, but also gain greater opportunities to influence the communities in which we live, and to contribute to and actively participate in society.

The Sustainable Development Goals can only become a reality by including people with disabilities – people like us – in the work towards attaining them.

Göran Alfredsson
Chairperson MyRight



MyRight's Chairman Göran Alfredsson

"Partnership is the fundamental building block of development cooperation. It is our way of strengthening ties within and between organisations working for sustainable development and human rights."

Swedish Association of the Visually Impaired

"Our partnership is based on mutual confidence and trust. Impaired hearing used to be unknown in Bolivia – we identified ourselves as either deaf or hearing. Our partnership with HRF and their hearing-impaired representatives has given us a role model – if they can do it, so can we!"

Joaquín Herbas Miranda, ASHICO

"The partnership with the Autism and Asperger Association is passionate. We share experiences and our families understand each other."

Sunita Maleku Amatya,
Autism Care Nepal

"Our partners in Nepal really are passionate about what they do in a different way from us. It's an inspiration."

Sara Bryntse and Hanna Bergström,
UH - Hard of Hearing Young People Sweden

"It gave our partner in Tanzania great hope to see that people in the wealthy Nordic countries have disabilities too. We share tough experiences and know how important it is to spend time with other parents and children in the same situation. That's what lies at the heart of our work, that shared experience."

Liiso Åkerberg, RBU

The partnership

MyRight's work rests on the partnership between a Swedish disability organisation and its counterpart in the country of operation. The partnership's strength is shared experiences and the challenges of living with an impairment.

The organisations learn from and support each other. In most cases, the Swedish organisation has existed for longer than the partner organisation and is thus able to contribute experiences and lessons learned from organisational development and advocacy work, for example. Knowledge of technical solutions and examples of ways in which people with disabilities lead free and independent lives in Sweden can often be inspiring and motivating.

The local partner organisations give their Swedish counterparts new perspectives and angles. Carina Petterson of the Swedish Autism and Asperger Association talks about how their partner Autism Care Nepal's approach serves as a role model in Sweden, especially when it comes to working with the families of children with autism.

The Swedish organisation and the partner organisation share experiences, circumstances and challenges. MyRight acts to facilitate member organisations in supporting their sister organisations in the countries in which MyRight operates.



Human rights for all

Human rights cover all areas of life. All human rights are interrelated and interdependent. Accessibility is essential for persons with disabilities to be able to exercise their human rights.

The statistics on the number of persons with disabilities in the world are incomplete but the World Health Organization (WHO) and the World Bank estimate that there are one billion people living with at least one impairment. Almost 80 % of them live in low-and middle-income countries.¹ These people are often the most marginalised with very limited opportunities to change their situation.

Injustice and discrimination against persons with disabilities may be due to a lack of knowledge, negative prejudices and attitudes towards disabilities. This may have to do with a sense of guilt and shame and it is not uncommon for families to hide family members away. Many children who are born with an impairment are abandoned to their fate and grow up without enough food, without a language and without human touch. It is not uncommon for children and adults with disabilities to live in complete isolation, dependent on others. Many do not even have their births registered, for example.

Disabilities are intimately linked to human rights issues. People suffer profound injustice when, because of their impairment, they are denied care, education, work and the opportunity to participate in politics.² In the same way, people are violated by being subjected to violence, abuse and prejudice because of their impairment.

A number of studies from different parts of the world have shown that people living with an impairment and their families, run a considerably

higher risk of suffering economic and social inequalities than others. For example, the labour market is largely closed to persons with certain disabilities and those who have managed to get a job face many challenges.

Girls and women face double discrimination

Girls and women with disabilities are hugely affected by social isolation, stigma, uneven power relations and a lack of support. They also run up to three times the risk of suffering violence and sexual abuse compared to other women.³

Women living with disabilities run a very high risk of experiencing socio-economic inequalities and

Summary

Human rights apply to all people, but many persons with disabilities do not have full access to their rights. This may involve the right to vote, to inherit, to enter into contracts or to have a say in their own life.

If everyone, including persons with disabilities, is to be able to exercise their human rights, be involved in and contribute to society, we need to remove the obstacles that exist, so make society accessible. We also have to ensure that everyone is treated equally under the law.

There is often good legislation in place but persons with disabilities are still excluded and face discrimination. In many countries, persons with particular disabilities are declared incapable and are unable to exercise their rights.

In a demonstration in Brussels in 2017 we see a man in a powered wheelchair with a table. He is smiling into the camera. On his chair there is a placard with the text "Fix the system, not me". Photo: Anna Morin

Poverty, impairments and disability

There are clear links between poverty and disability. It is not the disability itself that creates or consolidates the poverty, but the obstacles that arise between the person with a disability and surrounding society. The obstacles can be communicative, informative, physical and cognitive. They may also involve discrimination and attitudes that prevent people with disabilities from participating in society. One example of discrimination is where a school does not accept children with disabilities on the grounds that it would cost too much.

poverty. They have less opportunity to receive an education and find it harder to obtain work. Fewer than one in five women with disabilities in the world have a job. This is significantly lower than for men with disabilities and also much lower than for other women.⁴

These women face a number of obstacles that make it much more difficult for them to participate in decision-making processes. This is the case not only in politics but also in many organisations working with rights issues. Many organisations working for gender equality are not aware of the specific challenges faced by girls and women with disabilities.⁵

Equality in law

Many countries have good legislation, inclusive policies and good approaches. Despite this, exclusion, discrimination and poverty remain.

One example is Nepal's new Nepal Disability Rights Act from 2017, developed in accordance with the Convention on the Rights of Persons with Disabilities. Despite good legislation, in practice it is difficult or impossible for people with disabilities to exercise their rights due to poor accessibility, discrimination and derogatory attitudes, and many disputes have been brought before the courts. For example, there are several cases in which persons with disabilities have not been allowed to inherit from their parents.

Nepal's new Education Rights Act (2018), guarantees free schooling for all children. The aim is inclusive education, i.e. all children should be able to attend the same school and receive the support they need. However, there is a long way to go, for various reasons to do with finances, knowledge and attitudes, as well as the fact that the entire state apparatus is in the process of being decentralised.

Bolivia also has disability-specific legislation based on the Convention on the Rights of Persons with Disabilities. Here too, however, the law is poorly implemented in practice



due to discrimination and inaccessibility. One example of discrimination is the right to housing enshrined in the Disability Act. It is difficult for people with an impairment to gain housing because the income threshold required to sign a tenancy is often far above the usual earnings of a person with an impairment. Equality before the law and ability to obtain a loan are guaranteed in the Disability Act. However, few persons with disabilities are able to exercise this right due to inaccessible application processes and a lack of available information.

Rwanda has no disability-specific legislation, but all legislation, including the Constitution, prohibits discrimination and asserts equal rights in accordance with the Convention. Nevertheless, many persons with disabilities are discriminated against and are unable to assert their inheritance rights, rights of ownership or the right to enter into contracts, and encounter challenges when opening a bank account, for example. MyRight's country office in Rwanda says that many persons with disabilities suffer patronising and moralising attitudes from the people who are supposed to be supporting them. If they wish to

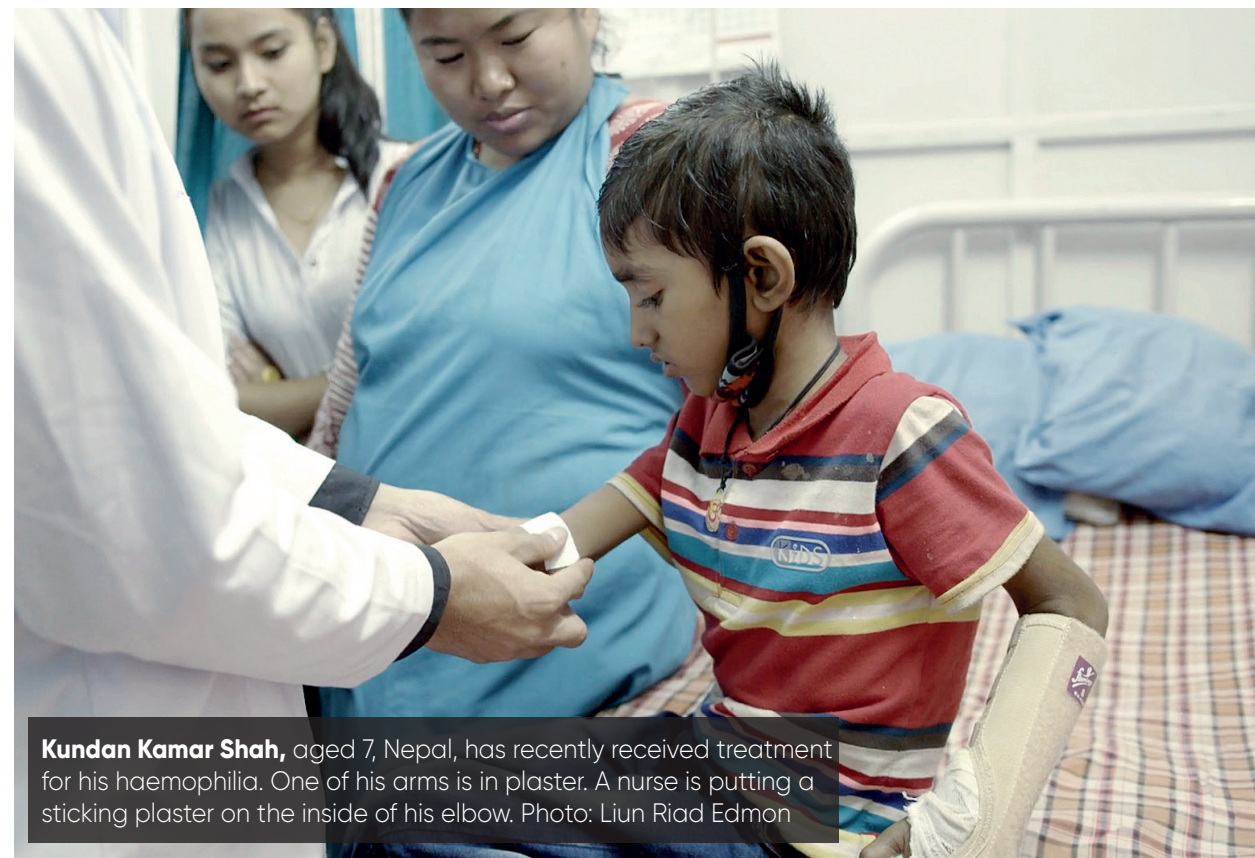
get married, for example, their wishes are often ignored.

Disabilities in legal terms

In countries such as Nepal and Bolivia, which have disability-specific legislation, which disabilities are defined as such is crucial.

Suraksha Thapa, of the Nepal Hemophilia Society, explains how important it has been for their members to have haemophilia recognised as a disability by the new act. This was the result of long-term lobbying in the project the society ran jointly with the Swedish Hemophilia Society (FBiS).⁶

Hemophilia is a painful impairment because it can lead to severe internal injuries and bleeding. Without treatment, people with hemophilia often find themselves leading isolated lives without daring to or being able to go out. Now that hemophilia is recognised as a disability, people with hemophilia can demand that the state pay the cost of treatments and spread information about hemophilia.



Kundan Kamar Shah, aged 7, Nepal, has recently received treatment for his haemophilia. One of his arms is in plaster. A nurse is putting a sticking plaster on the inside of his elbow. Photo: Liun Riad Edmon

“Society and politicians don’t think about persons with disabilities. There are no plans. This means you have to work very hard to get local authorities and society to have plans and visions to become more inclusive.”

Hamaddah Massour,
Swedish Association of the
Visually Impaired



Daniel Ndayishimiye, 15, Rwanda, stands at a school desk reading braille. Photo: Mia Munkhammar

In Rwanda, considerable progress has been made on accessibility in elections. Before the 2017 elections, the authorities and the disability movement’s umbrella organisations worked to educate people with disabilities about their civil rights, including the right to vote and the right to stand in general elections. There are now braille ballot papers, which help persons with visual disabilities to keep their vote secret. It is still a challenge for hearing-impaired and deaf people to gain and make use of information, making it much more difficult to make a free and informed choice.

When the Bolivian Disability Act was being drafted, the word for “hearing loss” was included in the bill right up until the final version, where the drafters did not recognize the word hipoacusia (hard of hearing) and consequently removed it from the text.⁷

The right to vote

Under the Convention on the Rights of Persons with Disabilities, the state must ensure that people with disabilities can effectively and fully participate in political and public life on an equal basis with others. This includes the right to vote.⁸

It cannot be taken for granted that persons with disabilities have access to their human rights and are able to exercise their right to vote. There are countries (such as the EU countries of Bulgaria, Malta, Poland and Slovenia⁹) where particular people with disabilities are not entitled to vote as they are declared incapable. And even when they do have the right to vote, as is the case in Sweden, for example, the election campaign is not accessible to everyone due to a lack of subtitles or sign language interpretation for election debates, which limits people’s opportunities to make an informed choice.

When voting, polling stations are often inaccessible, for example, often with steps without a ramp, which can make it difficult to vote at all, or ballot papers may only be readable by sighted people, placing the secrecy of the ballot box at risk. All these obstacles restrict the right to vote¹⁰ and people’s participation in and opportunity to influence the society in which they live.

“There are lots of negative prejudices and attitudes about disability in Nepal. Some say it is a punishment for a sin in a former life.”

Nirmala Dhital,
Nepal Disabled Women’s Association



Breaking the isolation

In order to break the poverty, isolation and discrimination in which many people with disabilities live, their autonomy needs to be improved, and they need to obtain information about their own impairment and the obstacles that arise in engaging with surrounding society.

One way of empowering persons with disabilities is to support and strengthen organisations run by persons with disabilities themselves. Strong organisations can serve as a platform for lobbying decision-makers and those in power, thereby achieving long-term and sustainable change. This makes it possible to break the cycle of poverty in which so many persons with disabilities live around the world.

National and international legislation are important conditions for change, but it takes more than that. Once the legislation is in place is when the real work starts – action and monitoring to make sure that what has been decided is actually implemented on the ground.

Good legislation is not enough

This theory of change and this tried and tested approach is supported by the 2030 Agenda and its SDG 17 (Partnerships for the goals) and Article 32 of the Convention on the Rights of Persons with Disabilities (International cooperation). It is also in line with the goal of Swedish international development cooperation to create opportunities for people living in poverty and under oppression to improve their living conditions.¹¹

All MyRight's partner countries have ratified the Convention on the Rights of Persons with Disabilities and several of them have introduced legislation in accordance with the Convention. This is when the real work begins, bringing the words on paper to life; putting them into practice so as to change the lives of thousands, perhaps millions of people.

The UN Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas Aguilar, uses the motto "embracing diversity". Her vision is a society in which we see all people's differences as assets. For this to become a reality, changes are needed in terms of norms, institutions, legislation and cultural practices and attitudes. In order to embrace diversity, we must remove the obstacles that result in persons with disabilities living in poverty. We must make it possible to create effective ways for persons with disabilities to engage in decision-making and seek new perceptions of what an impairment is, based on a human rights perspective.

It is vital that the organisations and their members familiarise themselves with legislation, conventions and policies so that they know what they are entitled to under national law and international law and can base their advocacy work on this.

Only by embracing diversity can we attain a world in which no one is excluded.

Ratification is a state's decision to legally commit to an international agreement, such as a convention. Sweden has ratified the Convention on the Rights of Persons with Disabilities.

Summary

To break isolation and escape poverty, non-discriminatory legislation is needed and it needs to be implemented in practice. Many countries have good legislation and institutions but isolation and poverty still remain.

Organising helps persons with disabilities to change this. Organisations can be places where people with the same disability find a sense of community and strengthen each other. They may be women's organisations where women with the same or different impairments come together. Joining forces in umbrella organisations at different levels is a powerful way of pooling resources and influencing decision-makers and other people in power with one voice.

Accessibility is vital if people with disabilities are to be able to exercise their human rights and participate in society.

Eugenie Bakundufite, Rwanda, sits at a school desk practising braille. She is surrounded by other pupils, of different ages, all with visual impairments. Photo: Mia Munkhammar

Ceaseless advocacy

Experience shows that nothing happens on its own, not even once the legislation and institutions are in place. It takes ceaseless advocacy to ensure that those responsible are aware of their commitments and obligations and that programmes and action plans are given the resources they need. Responsibility and sufficient resources are necessary to carry out programmes and plans and for duty bearers to be able to take responsibility and fulfil their obligations.

In Nepal, organisations including Autism Care consider that the government is not actually negative, but faces many challenges itself, including reforms, staff turnover and lack of resources, and that it lags behind when it comes to implementing new legislation.¹²

The Convention on the Rights of Persons with Disabilities is an important tool for forcing change, particularly in legislation. Organisations can use the Convention and the 2030 Agenda as lobbying tools. The major challenge is making sure that efforts do not stop at words on paper.

The many different roles of organisations

Disability organisations take on many different roles. Sometimes they are geared towards providing services not offered by the public sector, such as support in schools, interpreting services or assistance. They often act as schools for democracy and provide practical experience of leadership. This is important in paving the way for the organisations to engage in advocacy and thus change the situation of persons with disabilities for the better.

In societies in which people with disabilities are hidden away, organisations are dedicated to outreach activities to find people, inform them of their rights and offer them an opportunity to participate in the organisation's work and community. Disability organisations also often play a crucial role in breaking the isolation in which many persons with disabilities live. Isolation can be due to physical, cognitive or communicative disabilities or simply to attitudes

"When ASBAHT was looking for hidden children with disabilities, they found a girl who hadn't been outside for 15 years – she was as stiff as a stick, as thin as a splinter."

Liiso Åkerberg, RBU

and prejudices. Some of the people living in isolation have no language and minimal social contact. Some are placed in institutions where they often stay, abandoned by their families. The outreach and advocacy work of organisations is essential if these people are to emerge from their isolation.

Start from the beginning

Sometimes there is no organisation that gathers together people with a specific impairment, or the target group may already be members of a different organization. Building an organization from the start is a challenging business, and partnership with another disability organization can be valuable here. Several of MyRight's partnerships have involved building an organization and operations from the ground up. One example is the Swedish Association of Hard of Hearing People (HRF) which runs a project with ASHICO, the association of hearing impaired people in Cochabamba in Bolivia.

Role of relatives

Where people have autism or intellectual disabilities, it is often parents who organise to protect their children's rights. One example is the organization Autism Care Nepal, which was founded by mother Sunita Maleku Amatya. The organization runs a centre where parents can bring their children, obtain support and knowledge and learn how they can best support their child. They also work actively with information campaigns and political advocacy work at several levels.

The importance of women coming together

Persons with disabilities face the same gender equality challenges as the rest of the population. In organisations working for persons with disabilities too, the proportion of women in leading positions is low¹³ and girls and women living with disabilities are often excluded when decisions are made and work is conducted on issues related to their lives.¹⁴

As a rule, a woman with an impairment is primarily identified as a woman and not as a person with an impairment. Therefore, women's organisations often play an important role, both in terms of women having their voices heard and in feeling a sense of community and having the ability to strengthen each other.

Nepal Disabled Women Association, NDWA, brings together women with several different disabilities. Their services include leadership

training and sheltered accommodation for women who have been victims of violence and are subjected to threats. They can also help with vocational training so that women can earn their own income and increase their independence.

NDWA also works with advocacy and after many years of intense advocacy, NDWA is now invited to attend government committees and other fora for influence and participation.

Chair Nirmala Dhital says that the earthquake that struck Nepal in 2015 demonstrated that even women with disabilities can help in the event of a disaster. NDWA arranged temporary accommodation for women with disabilities in Kathmandu and Lalitpur who lost their homes in the earthquake. They were also able to provide help in the form of food and clothing from UNDP (the United Nations Development Programme).¹⁵



The Organisation ASBAHT runs training for parents and relatives of children with spina bifida and hydrocephalus at the MOI hospital in Dar es Salaam. ASBAHT is a national parent organisation in Tanzania that supports parents in seeking care for their children and provides information about aftercare and habilitation. ASBAHT is supported by the Swedish National Association for Disabled Children and Young People (RBU) and MyRight. Photo: Leena Similä



A view of the fronts of housing in Kathmandu, Nepal. The area is hilly and there are lots of paths and steps. Photo: Mia Munkhammar

Umbrella organisations

People’s voices are stronger when they act together and work in the same direction. Umbrella organisations serve as a platform for disability organisations to come together and benefit from synergies and coordination, in terms of resources, knowledge and influence. The umbrella organisations lobby the media and decision-makers at national and international level. Under the same umbrella, organisations can join forces and employ people who can speak the language of the authorities, apply for funding and engage in advocacy work.

In Nepal, MyRight has collaborated with the national umbrella organisation the National Federation of Disabled Nepal, NFDN, which works with advocacy, networking and support for policy development. They are also responsible for the steering committee which brings together participants from government and the parliament as well as civil society. The committee is an important platform for discussion and for reaching consensus on reforms and proposed legislation,

and cooperation within the committee has helped to shape the new constitution and legislation.¹⁶ After many years of political conflict in Nepal, many parties are urging mutual understanding and consensus. Disability organisations and public service providers both see the steering committee as a unique platform for discussion and attaining mutual understanding.¹⁷

In Rwanda, the government has recognized the umbrella organisation NUDOR (National Union of Disability Organizations in Rwanda) which gathers organisations for persons with disabilities together so that they can speak with a single voice and conduct advocacy work as a single entity. Working together makes the organisations stronger and more efficient and enables them to identify priority areas for advocacy. NUDOR has also mobilised previously unorganised groups and contributed to the inclusion of the disability perspective in different guidelines, strategies and programmes, and the inclusion of persons with disabilities in everything from policy work to Implementation and supervision. The experience of working with human rights nationally was

beneficial when writing an alternative report to the Committee on the Rights of Persons with Disabilities, which monitors compliance with the International Convention for the Rights of Persons with Disabilities. NUDOR has also previously mobilised unorganised groups to merge and form their own organisations, such as an organisation with people with deafblindness and one for people with albinism.

Alternatives to umbrella organisations

In the complex political landscape of Bosnia-Herzegovina, there is no national umbrella organisation. Here, MyRight works with regional disability coalitions. Working together means these are able to put together a single advocacy strategy. This has produced good results, both in terms of legislation and in terms of drawing up an alternative report to the Committee on the Rights of Persons with Disabilities.

In Bolivia, in addition to the national umbrella organisation, there are regional umbrella organisations which contribute to and influence the regional structures.

All umbrella organisations operate in a political context that is the result of the country’s history and which they have to take into account. In order to be an actor contributing to and influencing society, civil society must follow and adapt to the state’s organisation. The different ways of working reflect the recent history of the countries concerned. Rwanda is characterised by the Rwandan genocide (1994), Bosnia-Herzegovina by the Dayton Agreement (1995), Nepal by the Peace Agreement (2006), and Bolivia by the new Plurinational State of Bolivia (2006).

Challenges in umbrella organisations

In cooperation with umbrella organisations, it is important to remember who they formally represent and which groups may not be represented within the umbrella. They may also have difficulty in representing all their members equally. As in all organisations, umbrella organisations also face challenges concerning, e.g. gender equality, racism and class. It is important to be aware of these challenges to ensure representativeness and combat discrimination when in contact with these organisations.

The essential thing: accessibility

Accessibility is essential for persons with disabilities to be able to exercise their human rights. Accessibility is also essential to being able to live independently and participate fully and equitably in society.

Premises with no hearing loop, a building with no lift or a lecture without sign language interpretation exclude people. Information that is difficult to understand because the language contains difficult or complicated words or text that a person with a visual impairment cannot read creates barriers and imposes limitations. Images and videos without audio description for blind people exclude them entirely. Steps and thresholds are other examples that prevent people with a movement impairment from making their way around.

Obstacles in society limit opportunities to be involved in work, forging social relationships, and to participate in leisure and cultural activities, education and democratic processes. All people have the right to participate in society and an accessible environment is beneficial and makes life easier even for those who might not initially be the primary target group. In the same way, everyone benefits from clear, logical and relevant information. Organisations that are actively working to include everyone and have an accessibility mindset increase the quality of their operations.

There is a lot of advice about how we can increase accessibility in different areas and help is available on everything from website and document technology to how the physical environment can easily be adapted to meet different needs. The Swedish Agency for Participation has a great deal of advice at www.mfd.se. The website includes information on accessible premises, accessible information and communication. Different disability organisations can provide information about accessibility in relation to specific disabilities.

A basic rule is to be attentive and responsive to people's needs and ask the people affected themselves.



A child's hands close-up reading a book in braille.
Photo: Mia Munkhammar



Tools in work to improve access to rights

Applying a disability perspective or involving persons with disabilities in an organisation's operations is not difficult. There are several useful tools to include persons with disabilities at all levels and through all processes.

Rights-Based Approach – getting it right from the start

It is also in line with the objective of Swedish international development cooperation to create opportunities for people living in poverty and under oppression to improve their living conditions. This requires that we understand which people are living in poverty, how poverty is perceived and what the underlying causes are.

Carrying out a rights-based poverty analysis enables us to determine who the most vulnerable people are and who we should direct our interventions towards. These often include people with disabilities.

A Rights-Based Approach (RBA) or rights-based work is based on four principles:

- Non-discrimination
- Participation
- Transparency
- Accountability

We can come a long way by using RBA as a starting point and as a tool in development cooperation.

The principle of non-discrimination helps us to ensure that we do not discriminate or exclude anyone.

The participatory principle helps us to find out what the target group actually needs, and involving them at every step from the start of a project to its conclusion helps us to keep moving in the right direction. To enable the participation of persons with disabilities, it can be particularly important to think about accessibility, not least because information must be available to everyone who is expected to participate.

The principle of transparency helps to build trust among taxpayers and donors in Sweden, and among target groups and authorities in the partner country.

Every state that has ratified the Convention on the Rights of Persons with Disabilities is responsible for complying with it. To ensure accountability, we need to know how responsibility for the rights has been allocated. What is the responsibility of different government departments and which other authorities are relevant? What is the responsibility of municipalities and similar regional authorities? Is there any specific human rights authority and, if so, what does it do? The more we know about these aspects, the easier it is to hold the state accountable.

Summary

Applying a disability perspective or involving persons with disabilities in an organisation's operations is not difficult. There are good tools available and many organisations have a great deal of experience and advice.

Starting out from a rights-based approach means we can more easily identify those most in need of action and involve the target group in designing efforts to ensure that they get what they really need.

The 2030 Agenda and the Sustainable Development Goals clearly state that no one should be excluded or forgotten. The Convention on the Rights of Persons with Disabilities provides good tools and guidance to meet the goals for everyone.

Denana, Elvedina and other people in the Ružičnjaka organisation in Bosnia Herzegovina are in the kitchen dressed in aprons and chef's hats. Photo: Rebecca Hallqvist

The 2030 Agenda and the Sustainable Development Goals

Sustainable development can only happen if people's rights are met. The 17 Sustainable Development Goals (SDGs) apply to all people and all layers of society. There is a particular focus on reaching the most vulnerable and marginalised people – Leave No One Behind. It is simply impossible to attain the SDGs without including people with disabilities.¹⁸

It is the states that have signed the 2030 Agenda that will be called to account and must meet their undertakings. Many states are still ignoring the fact that a sustainable world will demand the inclusion of persons with disabilities. The disability perspective offers crucial transformative potential in turning this around. The Convention on the Rights of Persons with Disabilities is a good tool for achieving the objectives and ensuring that no one is left behind.

Leave No One Behind

Equality, equal opportunities for resources and development, can never be possible without including persons with disabilities. In order to meet the 2030 Agenda and the SDGs, everyone

must be included. The 2030 Agenda is inclusive and "Leave No One Behind" is a recurring theme.

Reliable statistics

The key to achieving success is the availability of reliable statistics on the situation in different countries. That is why one of the targets is to increase support in this area. The reason for increased support is to "significantly increase the availability of high-quality, up-to-date and reliable data, broken down by income, gender, age, ethnicity, migration status, disability, geographical location and other nationally relevant aspects." This target must be met in 2020.

The importance of reliable statistics is also emphasised in the Human Development Report 2016. It states that it is crucial that the international community obtain data on which groups lag behind, where they are located, and the causes of this.¹⁹

What are the Sustainable Development Goals?

On 25 September 2015, the United Nations Member States adopted the 2030 Agenda, a universal agenda that encompasses the SDGs. The 17 SDGs in turn have 169 targets and 230 global indicators. Disabilities are mentioned 11 times in the SDGs and seven of the 17 SDGs explicitly reference disability.

Over a 15-year period, up to the year 2030, the world's countries have undertaken to work together to achieve the SDGs and long-term sustainable development. Each country in turn will develop national indicators to measure and monitor the work. All the countries of the world choose how often they want to report their

implementation of the Agenda to the UN's High-level Political Forum (HLPF), held in New York each year.

The concept of sustainable development integrates the three dimensions of sustainability: social, economic and environmental.

In the SDGs, the world's leaders have committed themselves to achieving three things by 2030; Eliminating extreme poverty, reducing inequalities and injustices in the world, and resolving the climate crisis.



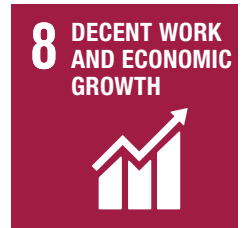
SUSTAINABLE Development Goals

Some of the SDGs that specifically address people with disabilities are:



SDG 4 is to ensure inclusive and equitable quality education and promote lifelong learning opportunities for all. It emphasises the need for educational environments adapted to children and adults with disabilities.

SDG 8 is to promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all. One of the targets to be achieved by 2030 is "full and productive employment and decent work for all women and men, including for young people and persons with disabilities".



SDG 10 aims to reduce inequalities within and among countries. One of the targets is to empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status by 2030.

SDG 11 is to make cities and human settlements inclusive, safe, resilient and sustainable. In order to create sustainable urban development, under SDG 11, the world must take particular account of disabled people, children, and the needs of older people.



Under SDG 17, the international community establishes that an intensive global commitment will be required to implement the 2030 Agenda.

Convention on the Rights of Persons with Disabilities (CRPD)

The Convention on the Rights of Persons with Disabilities is to promote, protect and safeguard human rights and fundamental freedoms for persons with disabilities. Of course, people with disabilities are also covered by other conventions and by the United Nations Universal Declaration of Human Rights. The Convention on the Rights of Persons with Disabilities aims to strengthen the protection that persons with disabilities already have under other conventions.

The aim is to remove the obstacles that prevent people with disabilities from exercising their human rights. The Convention on the Rights of Persons with Disabilities was adopted by the UN General Assembly 2006. In 2018, 177 states had ratified the Convention.

The Convention has played a key role in the entire global disability movement. Historically, persons with disabilities have been seen as recipients of

welfare, and as second-class citizens and disabilities have been seen as something to be cured or hidden away. The Convention is an important milestone in the history of disabilities and of human rights. The Convention entrenches an important shift in perspective in the view of persons with disabilities – from being considered passive recipients of welfare to being individuals with rights.

The Convention on the Rights of Persons with Disabilities (CRPD) consolidates and clearly sets out that human rights cover all people, regardless of the circumstances and wherever we live.

Once a country has adopted the Convention, society must start to be adapted to its requirements. It is the states that are responsible for ensuring that rights are respected and upheld. The international Committee on the Rights of Persons with Disabilities monitors compliance with the Convention, and all countries that have adopted the Convention must submit a regular report to the Committee describing how the Convention is being complied with. The Committee then makes its assessment with recommendations to the countries.

The Convention in accessible formats

It is crucial that the Convention and related documents are available in languages and formats that everyone can understand, otherwise it will be even more difficult to take on board its sometimes complex content. K. P. Adhikari, President of the National Federation of the Deaf Nepal, describes how difficult it is for deaf people to take in and use the Convention, recommendations and general comments because they are not available in sign language.²⁰ Sunita Maleku Amatya, President of Autism Care Nepal also tells us that it is difficult for people with autism to use the complex material. It needs to be provided in accessible formats, such as simplified language, pictograms or similar so that people with autism can understand its content, familiarise themselves with their rights and be able to apply the content of the Convention.²¹

MyRight conducts all its activities, including activities, seminars and meetings, on the basis of the Convention on the Rights of Persons with Disabilities. MyRight is involved with the disability movement in the countries in which it operates, in order to make the articles of the Convention a reality.

In programmes and projects, partners are supported to ensure that people with disabilities have access to their rights in accordance with the Convention. This is partly done by forming groups and regional networks, as well as by monitoring compliance with the Convention in various ways, and by conducting dialogue with governments when they write their national reports and by contributing to alternative reports from civil society.

The aim is always to strengthen the voices of persons with disabilities and to increase their participation in the development of society.

Use the Convention in national or local advocacy to make the state fulfil its obligations.

- Ensure that the Convention, its additional Protocols, recommendations and general comments are translated into your own language.
- Collaborate with other organisations working on human rights, strengthen each other and make use of each other's experiences and knowledge.
- Make sure that the above are available in different formats, including simple language to ensure that everyone is able to understand the content and be aware of their rights.
- Assert your right under Articles 4(3) and 33(3) to be involved in everything relating to persons with disabilities.
- Carry out training in human rights and the Convention on the Rights of Persons with Disabilities in particular to ensure that the target group/everyone is aware of their rights and how they can demand them.
- Gather together disability organisations to compile an alternative report to the Committee on the Rights of Persons with Disabilities in parallel with the regular reporting submitted by the state. Alternative reports are afforded great weight in the Committee's assessments.
- Follow up the Committee's recommendations to the government. Do not wait for the next report.

Article 4(3)

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

Article 33(3)

Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.



Preschool children playing in a schoolyard in Kabaya, a region in Western Rwanda. A boy with Downs syndrome looks into the camera. There are two other children standing next to him. They are holding hands. Photo: Mia Munkhammar

Suggestions for organisations in international development cooperation

1. Ensure that your efforts reach everyone. Make your activities and projects accessible to everyone and include the issue of inclusion in design, implementation and follow-up.
2. Ask your partner organisations if their members include people with disabilities and ask about their accessibility. Encourage cooperation with disability organisations.
3. Cooperate and engage in dialogue with organisations working for the rights of persons with disabilities and benefit from their knowledge.
4. If there are donor networks in the country, make sure that there is someone with knowledge of the impairment able to share their knowledge.
5. Do not get bogged down in analysis work, but make sure that the strategies you devise are feasible.

Notes

1. World Report on Disability, WHO and the World Bank, 2011
2. World Report on Disability, WHO and the World Bank, 2011, p. 9
3. Disability, Poverty and Development, DFID, 2000, p. 3
4. World Report on Disability, WHO and the World Bank, 2011, p. 237
5. Still left behind: Pathways to inclusive education for girls with disabilities, UNGEI, 2017, p. 7
6. Interview with Suraksha Thapa, Nepal Hemophilia Society, Kathmandu (02.11.18)
7. Interview with Javier Salguero, head of the disability unit at the ministry of justice in La Paz, Bolivia (February 2012)
8. Article 29, Participation in political and public life, UN Convention on the Rights of Persons with Disabilities (CRPD)
9. Who will (not) get to vote in the 2019 European Parliament elections?, EU Agency for Fundamental Rights, 2019, p. 7
10. United Nations Convention on Civil and Political Rights Article 25(b) and Convention on the Rights of Persons with Disabilities, Article 29(a)
11. Strategy for Sweden's development cooperation in the areas of human rights, democracy and the rule of law 2018–2022, Ministry of Foreign Affairs
12. Interview with Sunita Maleku Amatya, President of Autism Care Society Nepal, Kathmandu (01.11.18)
13. Disability and gender based violence, ADD
14. Making the SDGs count for women and girls with disabilities, UN WOMEN, 2017, p. 2
15. Interview with Nirmala Dhital, Chairperson of the Nepal Disabled Women Association, Kathmandu (02.11.18)
16. Interview with Sudarson Subedi, president of the National Federation of Disabled Nepal, Kathmandu (04.11.18)
17. Interview with Roj Nath, Speaker of Parliament and Steering Committee Member 2011–2015, Kathmandu (02.11.18)
18. Realization of the sustainable development goals by, for and with persons with disabilities, United Nations, 2018
19. Human Development Report Overview, UNDP, 2016, p. 5
20. Interview with K.P. Adhikari, president of the National Deaf Federation Nepal, Kathmandu (04.11.18)
21. Interview with Sunita Maleku Amatya, President of Autism Care Society Nepal, Kathmandu (01.11.18)

“Only by embracing diversity can we attain a world in which no-one is left behind.”

Catalina Devandas Aguilar,
United Nations Special Rapporteur on the
Rights of Persons with Disabilities



Human rights apply to all people, but many persons with disabilities do not have full access to their rights. This may involve the ability to participate in elections, the right to inherit, sign contracts or to speak for themselves.

In this report, you can read about the situation for persons with disabilities around the world and gain ideas on how international development cooperation can increase inclusion, prevent discrimination and help everyone to fully enjoy their human rights.



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